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ABSTRACT

This document presents one module in a set of training resources for trainers to use with parents and/or professionals serving children with disabilities; focus is on coping with loss and change. The modules stress content and activities that build skills and offer resources to promote parent-professional collaboration. Each training module takes about 2 hours to deliver. The module guide has eight sections: a publicity flyer, topic narrative, overview, trainer agenda, activities, summary, bibliography, and evaluation. Introductory information explains how to use the modules including conducting a needs assessment, planning the training, selecting the training module, implementation, evaluation, and followup. Objectives of this module are: (1) become familiar with states of coping and their commonality to all individuals, (2) discuss the states of coping relative to their own personal experiences, (3) recognize that the process of coping with loss and change is normal and each individual goes through the states in their unique manner, and (4) provide information and resources. A bibliography identifies seven books, magazines, or other resources. (DB)

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COPING with LOSS and CHANGE

EC 222 049

California State Department of Education
Bill Honig, Superintendent of Public Instruction
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California State Department of Education
Special Education Division
Program, Curriculum and Training Unit

Presents A Module on:

Coping with Loss and Change

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1988

This module, as well as thirteen others, were produced under the direction of Karl E. Murray and Susan Westaby of the Program, Curriculum and Training Unit, Special Education Division, CA State Department of Education. The modules are being field-tested throughout 1988. During this field-test stage, they are available by sending $ 5.00 for each module (includes tax and mailing) to: Parent Training Modules, CA State Department of Education, P.O. Box 944272 - Room 621B, Sacramento, CA, 94244-2720. Make checks payable to Parent Training Modules.

INTRODUCTION

The Parent/Professional Training Modules have been developed to serve as a core set of training resources for trainers to use primarily with groups of parents. Some of the trainings were designed specifically for combined groups of parents and professionals, and all the trainings can be adapted for use with parents or professionals as separate or combined audiences. The training modules in the series focus on content and activities that build skills and offer resources to promote parent-professional collaboration to ensure quality education for all students with disabilities. There are fourteen training modules in this series:

Parent Professional Collaboration
Parental Involvement
Stress and Support in the Family
Coping with Loss and Change
Parent Support Groups
An Effective Community Advisory Committee
Community Advisory Committee Leadership Training
Communication Skills
The Individualized Education Program: Rights and Responsibilities
Placement in the Least Restrictive Environment
Training for Professionals Working with Families
Parent Professional Collaboration in Planning for Employment
Transition Planning
Interagency Collaboration: The Parents' Role

Each training module has eight sections:

Flyer
Topic Narrative
Overview
Trainer Agenda
Activities
Summary
Bibliography
Evaluation

Within each of these sections there are these materials:

Flyer - The Flyer highlights what participants can expect to learn by attending the training. It can be personalized for each training by adding date, time, and location in the appropriate spaces.

Topic Narrative -- The Topic Narrative contains content information specifically for the trainer. Trainers use the information to enhance their knowledge and understanding of the subject matter of the training module.

Overview -- The Overview contains the goals and objectives for the module; and the content and presentation strategy for each activity contained within the module.

Trainer Agenda -- The Trainer Agenda contains details of trainer and participant activities, materials and media. It is a suggested agenda that trainers can personalize to fit their style and the specific needs of the participants. A few modules that deal with sensitive or difficult content have Trainer Tips included in the Agenda section.

Summary -- The Summary contains highlights of all the content information presented in activities within the training. The Summary was designed to provide information to prospective participants and to workshop planners.

Bibliography -- The Bibliography contains the names of books, magazines and other resources that were used as references in developing the training modules and may serve as a list of suggested reading materials for trainers as well as participants.

Evaluation -- The Evaluation contains questions that directly assess the objectives of the module as well as some general questions to evaluate the usefulness of materials and trainer effectiveness.

The Parent/Professional Training Modules have been designed to be a flexible and expandable resource for trainers of parents and professionals. It can be housed in binders or in file folders and rearranged as needed. Trainers are urged to add articles, resources and other materials that will make each training reflect their individual style and meet the needs of the participants.

HOW TO USE THESE TRAINING MODULES

Conduct a Needs Assessment:

Gather as much information as you can about the groups that you will be working with. The following types of questions may help:

Does the group meet regularly or is it assembled specifically for the purpose of this training?

What does the group want to accomplish? Does it have a stated goal? Are there a set of outcomes that the group wants to achieve?

Who is involved in the group (agencies and organizations)?

If the group is an ongoing group, how is the group organized? (officers, executive committee, standing committees, task groups, etc.)

What has the group already done? What training has the group already received?

What is the group working on now?

How does the group get things done?

Has the group conducted a needs assessment to determine the group's need for training and the training topics of interest?

Plan the Training

Typically, this is a dialogue between the trainer and the client. Often, the client will have a specific topic or activity in mind. Sometimes additional topics will be suggested during the needs assessment process when the trainer probes to get more information. The trainer can share a list of module topics and/or several module summaries to aid the client in selection of a topic(s) from the series.

Select the Training Module

The Parent/Professional Training Modules offer a wide selection of topics and activities. The trainer can select the module that deals with the topic chosen by the client.

Review the Training Module

The module provides the core activities and a suggested trainer agenda. The trainer can adjust both to reflect their individual style and the needs of the client.

Identify Additional Resource Materials

The trainer may add to these presentations other materials to the core training module. Often participants can provide pertinent sample materials.

Deliver the Training

The Parent Involvement Training Modules are best delivered by a training team of a parent and a professional. Facilitation is enhanced by the team as each member of the team brings strengths, skills and knowledge as they enhance each others presentations.

Evaluate the Training

Evaluation is an essential element of any training. Each module includes an evaluation that assesses the specific objectives of the module and the usefulness of materials. These evaluations can assist the trainer in refining the module content and modifying presentation style, if required.

"Follow-Up" the Training

It is a good practice to follow-up any training with a personal visit, letter, or a phone call. The trainer may wish to keep a list of names, addresses, and phone numbers of participants to facilitate follow up. The follow up usually consists of discussion about how the training may have impacted the client's personal or professional life. Clients may express the desire for further training and/or materials and resources.

Coping with Loss and Change

(For All Interested and Involved Parents)

You, as a participant, will learn about:

- the "good grief" cycle
- the states of coping
- how your personal experiences relate to the state of coping
- how each person goes through the states of coping in their own way
- information and resources to help you cope with loss and change

Day and Date:

Time:

Location:

For More Information, Call:

Please Come

Coping With Loss And Change

Topic Narrative

Much has been written about the emotional reactions of parents to having a child with a disability. These parental responses or states are:

1. Shock
2. Denial
3. Guilt
4. Anger
5. Sadness
6. Objectivity
7. Maintenance/Resolution

It is important to remember that the coping process is not a static one with a clear beginning or end.

While the model can provide a framework for understanding, it should not be assumed that we can now predict parental reactions in a cut and dried way. Models, by their very nature, clarify situations by oversimplifying. Any number of personality and situational variables can come into play to modify, distort, slow down, accelerate, or subvert the normal coping process. Some obvious factors to keep in mind are: personality type, past experience with handling crises and success, socioeconomic status, marital relationship, number of siblings and birth order of handicapped child, age of child when handicap is identified, type and clarity of diagnosis, the manner in which parents were informed, availability of appropriate services, the intensity and number of other stresses at the time, and the cultural meaning of the handicap.

When a child with a disability is born, the fantasies of having a "perfect" baby must be set aside. Gradually, this fantasy of the normal child is replaced by the reality of the situation and the family can begin to accept the child that was born to them.

The idea of the death of a dream is one that applies to a whole range of human functioning. Again, it is helpful to parents if they can conceptualize their experiences in coming to grips with the birth of a handicapped child as part of a normal process of people coping with change: it is "normal" in the sense of common and expected rather than deviant or pathological; it is "coping" in the sense that the parents of handicapped children are attempting to be goal-oriented and problem-solving; it is a "process" in the sense of moving from one identifiable step to another through a series of stages (Sieffert, 1978). In this case, the "change" is in the form of the parent adjusting to the reality of not having the wished-for normal child.

This emotional adjustment that a person goes through has been termed "grief work." Grieving is the natural human response to a significant loss, be it the loss of a loved one, a cherished possession, a job, a dream, a homeland, or a part of the body. "Grief work" is a process that extends over a long period of time. It is not simply the sadness that most people associate with mourning, but rather a range of emotions that all humans go through as they try to recognize and accept the loss, death, change, or disappointment in their lives.

Shock

Shock is the normal reaction to finding out that the child is handicapped. Many parents have described this as an actual numbness, or a feeling of calm. The shock serves an adaptive function, in that it enables the person to emotionally "catch his/her breath."

Denial

Denial is a psychological mechanism which protects the parent from the overwhelming pain and disappointment that go with the realization that they have a handicapped child. Denial can be obvious or subtle. Denial statements such as "He'll outgrow it" or "it's just a vitamin deficiency" can be easily recognized. More subtle forms exist. For example, the parent accepts the handicap on the surface, yet has unrealistic expectations about the child's future achievements: "I know my child's retarded, but we are looking forward to the time when he/she will attend college." Many times parents will go from professional to professional looking for one that will say nothing is wrong. This is not to say that "shopping around" is bad. It may come from an honest effort to understand their child's condition. When the searching is motivated by denial, however, it is the parent's attempt to avoid the painful reality of the handicap.

Guilt

When the reality can no longer be denied, parents enter a phase where they question what they did to cause their child to be handicapped. If a parent produces a handicapped child, he may feel it is because he/she has sinned or is inadequate. Parents explore all possibilities. Was it something they did or didn't do? Or worse yet, do they have an inherent defect?

Anger

This phase may be interwoven with the previous one, since guilt is often thought of as anger turned inward and directed at the self. The parent continually debates with him/herself whether the blame belongs to him/her or to the outside world. Anger may be directed toward the spouse. Searches are made into the family background for possible clues. Bitterness may arise towards parents of non-handicapped children. Anger may be expressed toward professionals working with the child, or the child him/herself. The anger is an outgrowth of the frustration of attempts to answer the impossible question, "Why did this happen to me?"

Sadness

It is during this phase that a parent experiences the sense of loss and sadness that people frequently associate with grieving a death. In this case, it is the symbolic death of the healthy, perfect child for which they had hoped. The parent may weep, be irritable, suffer loss of appetite, or experience insomnia. While this is an emotionally difficult and draining period, it helps to prepare the parent to let go of the fantasized normal child and accept the child that she/he does have.

Objectivity

This is a period in which parents begin to explore the nature of the handicapping condition. They attempt to learn all they can about the particular disability. They may put their energy into some cooperative venture for the purpose of getting better services for their children.

Maintenance/Resolution

This is the idealized final stage that signals not the acceptance of the disability, but acceptance of the child. The parent becomes realistic about the impact of the handicap on the child's life, and is able to separate the effect of the disability from the child her/himself. The parent is able to accept the limitations of the disability without having to look for compensation, nor does she/he have to rationalize about the supposed advantages of these limitations. The parent approaches resolution when he/she can see his child as a child first, and handicapped second. This is also a phase when the parent is able to recognize strengths in him/herself.

Overview

The main goal of this module is to understand the process of coping with loss and change.

Objectives

1. Become familiar with states of coping and their commonality to all individuals.
2. Discuss the states of coping relative to their own personal experiences.
3. Recognize that the process of coping with loss and change is normal and each individual goes through the states in their unique manner.
4. Provide information and resources.

Objective Number	Suggested Minutes	Content	Presentation Strategy
	10	Introduction, Objectives and Agenda Review	
	15	Warm up Activity	
1	30	States of Coping	Lecturette
2&3	20	Individual Experience with Loss & Change	Small Group Discussion
	10	Break	
2&3	15	Individual Experience with Loss & Change (cont.)	Large Group Discussion
4	10	Ken Moses (Information)	Lecturette
4	20	Articles	Lecturette and Large Group Discussion
	10	Conclusion and Evaluation	
	140		

Trainer Tips

This module deals with many sensitive issues around parenting a child with a disability. Trainer(s) need to be:

- individuals who have personal experience dealing with these issues and who have experience in working with parents.

- aware that the presentation on "States of Coping" may bring up feelings that participants have not previously acknowledged.

- skilled in communication techniques to effectively deal with feelings of the participants that may arise.

Suggested Trainer Agenda

WORKSHOP TITLE: Coping with Loss and Change

DATE: _____ PAGE: 1

PRESENTERS: _____

CLIENT: _____

GOAL: To understand the process of coping with loss and change.

1. Become familiar with the states of coping and their commonality to all individuals.
2. Discuss the state of coping relative to their own personal experience.
3. Recognize that the process of coping with loss and change is normal and each individual goes through the states in their unique manner.
4. Provide information and resources.

TIME	WHO	TRAINER ACTIVITIES/CONTENT	PARTICIPANT ACTIVITIES	HANDOUTS MEDIA
10 minutes		Welcome Introductions Objectives and Agenda Review (on charts) Display Objectives and Agenda on Chart Paper		Chart Paper Pens Tape Chart of Objectives and Agenda
15 minutes		"Warm up" . . .whip (Designed to bring participants in touch with feelings). Parents. . . . . "Having a child with special needs sometimes feels _____." Professionals . . . ."If I had a child with special needs I would feel _____." When group is parent/professional . . . . "Having a child with special needs is/would be _____."	Seated in circle without physical barriers...when possible	

Suggested Trainer Agenda (Continued)

TIME	WHO	TRAINER ACTIVITIES/CONTENT	PARTICIPANT ACTIVITIES	HANDOUTS MEDIA
30 minutes		<u>States of Coping</u> Activity/Handout 1 - Part I Lecturette Video - "What About Tomorrow" Distribute Handout 1 Introduction to Video: The joy and excitement of your new arrival explodes with the announcement: your child is handicapped. Or, in later years, your expectations for your child's success in school is shattered with: there seems to be a problem. "What About Tomorrow" deals with the anxieties, frustrations and hopes of parenting "an exceptional child". A core of parents present their personal and public quests for understanding, acceptance and help in preparing for the futures of their families. The topics include the universal feelings of shock, denial, anger, numbness, self-blame, and "Why, Me?" syndrome. The parents interviewed pull no punches in talking about how all of the above are manifested in anxiety and depression which can affect family relationships and cause time, energy and money concerns. Please refer to your Handout and see if you can identify states of coping of parents.	View chart/OH and video	VCR Handout 1 Video - "What About Tomorrow"
(30 minute alternative)		<u>The Coping Process</u> - (If no video ...) Activity/Handout 1 - Part I Lecturette Distribute Handout 1 When a handicapped child is born the fantasies of having a "perfect" baby must be set aside. Gradually, this fantasy of the normal child is replaced by the reality of the situation and the family can begin to accept the child that was born to them. In effect, there has been a symbolic death in that this fantasy must be "laid to rest."	Listen	Handout 1

Suggested Trainer Agenda (Continued)

TIME	WHO	TRAINER ACTIVITIES/CONTENT	PARTICIPANT ACTIVITIES	HANDOUTS MEDIA
		The idea of a symbolic death is one that applies to a whole range of human functioning. Again, it would be helpful to parents if they could conceptualize their experiences in coming to grips with the birth of a handicapped child as part of a normal process of people coping with change: it is "normal" in the sense of common and expected rather than deviant or pathological; it is "coping" in the sense that the parents of handicapped children are attempting to be goal-oriented and problem-solving; it is a "process" in the sense of moving from one identifiable step to another through a series of stages (Sieffert, 1978). In this case, the "change" is in the form of the parent adjusting to the reality of not having the wished-for normal child. This emotional adjustment that a person goes through has been termed "grief work." Grieving is the natural human response to a significant loss, be it the loss of a loved one, a cherished possession, a job, a dream, a homeland, or a part of the body. "Grief work" is a process that extends over a long period of time. It is not simply the sadness that most people associate with mourning, but rather a range of emotions that all humans go through as they try to recognize and accept the loss, death, change, or disappointment in their lives. Note to Parent Trainer: Go through the states of coping using personal examples to illustrate the various stages. It is important to indicate that one does not necessarily go through the states in a logical progression (i.e. 1,2,3) and once in maintenance/resolution one may go back to an earlier state. Bridge to more clinical descriptors of "stages" by saying..."let us take a minute to go through some descriptors of each of the states in the model."		

Suggested Trainer Agenda (Continued)

TIME	WHO	TRAINER ACTIVITIES/CONTENT	PARTICIPANT ACTIVITIES	HANDOUTS MEDIA
		Shock An actual numbness, or a feeling of calm. The shock serves an adaptive function, in that it enables the person to emotionally "catch his/her breath." *Denial* Denial is a psychological mechanism which protects the parent from the overwhelming pain and disappointment that go with the realization that they have a handicapped child. *Guilt* When the reality can no longer be denied, parents enter a phase where they question what they did to cause their child to be handicapped. *Anger* The parent continually debates with him/herself whether the blame belongs to him/her or to the outside world. *Sadness* It is during this phase that a parent experiences the sense of loss and sadness that people frequently associate with grieving a death. *Objectivity* This factor characterizes a period in which parents begin to explore the nature of the handicapping condition. They attempt to learn all they can about the particular disability. They may put their energy into some cooperative venture for the purpose of getting better services for their children.		

Suggested Trainer Agenda (Continued)

TIME	WHO	TRAINER ACTIVITIES/CONTENT	PARTICIPANT ACTIVITIES	HANDOUTS MEDIA
		Maintenance / Resolution This is the idealized final stage that signals not the acceptance of the handicap, but acceptance of the child. The parent becomes realistic about the impact of the handicap on the child's life, and is able to separate the effect of the disability from the child her/himself.		
20 minutes		<u>Individual Experiences with Loss and Change</u> Activity 1 - Part II Small Group Discussion The participants will have just viewed the video or listened to the presentation. Trainer will divide participants into groups of 3-5. Groups are instructed to discuss reactions to video/presentation and discuss personal experiences.	Divide into small groups (3-5).	
10 minutes		Break		
15 minutes		<u>Individual Experiences with Loss and Change</u> Activity 1 - Part III Large Group Discussion - Debrief Participants will rejoin large group.Trainer will debrief group by asking questions like: What were some commonalities? Did anyone find out something new? Was that a good experience? How did that feel?	Discuss questions	Questions on Chart Paper posted on wall

Suggested Trainer Agenda (Continued)

TIME	WHO	TRAINER ACTIVITIES/CONTENT	PARTICIPANT ACTIVITIES	HANDOUTS MEDIA
		The presenter should circulate between small groups and listen to concerns. The discussion may bring up feelings that parents have not been in touch with or acknowledged. The presenter needs to be sensitive to the emotional issues and acknowledge and accept the feelings that arise. The presenter should not be judgmental. The presenter may say: "I can see you are hurting." "That must have been difficult for you." "I hear Mary and Jane talking about the same thing. There seems to be a lot of commonality of experiences." The presenter should be emotionally in tune with group at this time. The presenter can say: "You need to know that you are not unique in your feelings. Anyone who has experienced change, loss or crises has been in touch with this process in some way." Many professionals have written about the coping process. We have some handouts that will provide more information.		
10 minutes		<u>Ken Moses Information</u> Activity /Handout 2A and 2B Lecturette Distribute Handout 2A and 2B Ken Moses speaks frequently of "ENUF" E - Empathy N - Non-Judgmental U - Unconditional F - Feeling Focus His most significant statement is: "The only thing we can lose in this life is the loss of a dream."	Large group	Handout 2A and 2B

Suggested Trainer Agenda (Continued)

TIME	WHO	TRAINER ACTIVITIES/CONTENT	PARTICIPANT ACTIVITIES	HANDOUTS MEDIA
		Trainer might talk a bit about the dream they had for their child. Both the child with special needs, as well as the "normal child." - There is no comparing pain and grief because you have no idea how big my dream was and I have no idea how big yours was. - No two people grieve the same. Successful grieving needs another person to share with. (See: Ken Moses' Guideline for the Sharing Process.) - Pain not let out turns to anger; anger held in turns to guilt. Look at people who are angry or guilty; maybe *no* one has ever *heard* their *pain*. * Note: For many professionals, the choosing of this profession may have been precipitated (related) by a loss in their own lives. Trainer discusses Ken Moses and his work in this topic. Go through handouts and discuss their relevance.		
20 minutes		<u>Articles</u> Activity/Handouts 3A and 3B Lecturette and Large Group Discussion Distribute Handout 3A and 3B Discuss Handouts 3A and 3B. Trainer should bring important points/ passages to attention of participants.	Review Handouts Listen, Discuss	Handouts 3A and 3B
10 minutes		<u>Conclusion</u> Restate Objectives. Thank Participants. Complete Evaluation/Handout 4.	Complete Evaluation	Handout 4

Coping with Loss and Change
Activity/Handout 1
Lecturette
30 Minutes

States of the Coping Process:

Guidelines for the Sharing Process Between Parents and School People

1. Always be aware of the dynamics of grieving; it is easy to forget the process of grief when faced with intense emotion.

2. Review your own personal strengths and weaknesses around grieving past significant losses of your own.

3. Clarify and practice focusing on the differences between a *feeling* and an *action*. Many actions can be immoral, illegal, unethical, insensitive, and inhumane; feelings are part of being human, crucial to dealing with loss, and, therefore, should not be judged or criticized.

4. Try to avoid answering direct questions that are of a general or predictive nature, because parents are usually more interested in having their concerns heard than in getting answers.

5. Try to remember you are not totally responsible for correcting the child's disability, nor the trauma that the disability brings to the family. Limit your concerns to the areas that fall within your professional role.

6. Try to separate the factual statements from the feeling statements that are both received and sent by you. It helps to maintain consistency in the types of communication between parents and school people.

7. During all your interactions do not ignore or abandon your professional convictions, recommendations or program guidelines; the direct educational services offered the child are always the first priority.

**Note: One cannot grieve alone. Successful grieving appears to be dependent upon supportive human interactions.

Adapted from Kenneth L. Moses, "The Impact of Initial Diagnosis: Mobilizing Family Resources." In J.A. Mulick and S.M. Pueschel (Eds), *Parent-professional partnerships in developmental disability services*. Cambridge: The Academic Guild Publishers, 1983.

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2

The Impact of Initial Diagnosis: Mobilizing Family Resources

Kenneth L. Moses

Introduction

The elements that foster growth in developmentally disabled children are no different from those needed by any other child. Children grow as a result of a complex interaction of physical, social, emotional, and cognitive elements. Most of the professionals involved in the habilitation of impaired children subscribe to the basic tenets of Holism, i.e., to the belief that one must deal with a whole child (Friedlander, Sterritt, & Kirk, 1975). For example, a professional who attends exclusively to a child's learning mechanisms is doomed to failure. A child is not a random collection of separate parts. Children are a unified and complex integration of many facets which each influence the other. For this reason, treatment approaches for developmentally disabled children need to address all parts of the child.

Parents are one part of a child's complex makeup. They are an element of the unified whole that comprises "the child." It is as futile to separate parent and child conceptually as it is to separate hydrogen from oxygen in water. Separate them and the original "subject" ceases to exist! The habilitation of impaired children must include the parent as an integral component of the whole child.

This chapter focuses on the relationship between the professional and

parent in the developmentally disabled child's habilitation process. In particular, it will examine those aspects that are often counterproductive to habilitation in the medical, special education, and therapy areas.

For many years parents of impaired children were actually excluded from the treatment process involving their children (Buscaglia, 1975). When they were finally brought into the process, the professionals who dealt with them often had little understanding of family dynamics. The emotional impact on the parent of having an impaired child was neither acknowledged nor addressed clinically. Further, the parents themselves had little understanding of what was happening to them or their family. The unfortunate outcome of this universal social/emotional ignorance was stressful interactions and hurt feelings. The following are examples of such feelings shared with "third parties"

> From a parent: "I'll never forget the doctor's incredible insensitivity..."
> From a professional: "If it wasn't for this hysterical, overprotective mother..."
> From a parent: "You get the feeling that they [the professionals] don't care about you or the kid; all they care about is keeping their job and avoiding hassle."

For over a decade many habilitation and rehabilitation professionals concerned with children suffering from developmental disabilities have become aware that they cannot treat a child's sense, function, or limbs in isolation (Friedlander et al., 1975). Programmatically it is becoming more evident that the Holistic approach has been generally accepted as *the* way to approach child development. Children, not functions, develop and grow. Such thinking has been the impetus behind both research and clinical applications of the early intervention concept with developmentally disabled children. The earlier the intervention, the more contact between parent and professional. Understanding the parent-professional relationship is as important to the habilitation of children as understanding any other function involved in a multidisciplinary approach.

The implementation of a truly Holistic approach to habilitation is extremely difficult. No professional can be trained to perform in all areas. Actual interdisciplinary cooperation requires a level of trust, respect, and confidence that is seldom seen. Habilitation professionals are frustrated by slow progress, hard-to-define successes, criticism from all sides, and stressful work environments that reflect the enormous responsibility of habilitating developmentally delayed children. Within this context, many professionals feel that parental feelings pose a powerful threat to a successful Holistic habilitation program (Brazelton, Koslowski, & Main, 1974). Again and again,

it becomes evident that parents and professionals have a substantive *shared* challenge to habilitate the developmentally delayed child.

There can be preexisting differences between parents and professionals that make it difficult for them to relate to each other. People come from varied religious, ethnic, racial, social, economic, and educational backgrounds. Sometimes these differences alone preclude comfortable parent-professional relationships. However, problems of so general a nature are seldom at the core of communication breakdowns.

Parents of developmentally disabled children, particularly right after an initial diagnosis, experience powerful feelings that dramatically influence their relationships with professionals who work with their children (Moses, 1977). In addition, most professionals feel intense emotional involvement in their work and have feelings that dramatically affect how they relate to parents. These emotional and interactive dynamics will be addressed in this chapter, along with recommendations aimed at mobilizing family resources after the parents receive the initial diagnosis.

Parents, Impairment, and Grief

When parents await the birth of a child they generate dreams about who that child will be *for them*. Often such dreams are of a very personal nature that is central to the parents' lives. The experience of anticipating the birth of a child is a primitive one that stirs deep feelings. Unfulfilled needs, yearnings for the future, struggles with personal deficiencies, and intense fantasies can all be attached to this yet-to-be-born child. For these reasons the attachment to the expected child and the parental dreams are inseparable (Moses, 1981)

When an initial diagnosis of developmental disabilities is received by a parent, a grief process begins. The parental dreams are almost always shattered by learning of the disability. To be actualized, dreams generally require a wholly intact child. Therefore, the initial diagnosis often marks the destruction of a cherished and significant dream. In order to continue with their lives the parents must grieve the loss of their dreams. Unfortunately, that loss is often so personal and elusive that few people are consciously aware of what is happening. Indeed, the parent frequently does not understand the process and finds that there is much confusion in addition to the feelings of grief.

Grieving is the process through which an individual can separate from a significant lost dream (Moses, 1977). Grieving stimulates a new look at one's social, emotional, and philosophic structures. Grieving facilitates personal growth through a reevaluation of core-level values and attitudes. Unless they

grieve, parents cannot separate from the dream attached to a lost person or "object" and, in essence, die with whomever or whatever is lost. Such people lose a present and future orientation and focus only on the past—on the "good old days" before they sustained the loss.

Grieving is primarily an emotional process. The feeling states experienced are not epigenetic; that is, they have no specific order, one is not a prerequisite for another, and, indeed, some can be felt simultaneously (Moses, 1981). Grieving starts spontaneously and appears to require no learning period. The feelings that result seem to be intrinsic, cross-cultural, and are even evidenced in some animals (Lewis & Rosenblum, 1974).

The feeling states of grief include denial, anxiety, guilt, anger, and depression. There is no true order to these feelings, although denial and anxiety are often experienced first, with depression, guilt, and anger usually clustering together. Two, three, and even four feelings can be felt simultaneously or alternately. Feeling states can return and be reexperienced in new contexts.

Successful grieving appears to be dependent upon significant human interactions; that is, one cannot grieve alone. The support that a parent of an impaired child needs in order to successfully grieve may come from the professional who is working with the child as well as from the spouse, friends, religious groups, the community, and/or parent organizations. Unfortunately, many of the prevalent cultural injunctions in western society inhibit the spontaneous grieving process. The emotions that are displayed as part of the grieving process are often rejected by both the grieving individual and by "supportive" others. Ironically, many of the people trying to help bereaved individuals inadvertently frustrate the process. They easily reject the feeling states of denial, anxiety, guilt, depression, and anger as being pathologic. Most do not recognize such states as being part of a normal and necessary grief experience. Often they respond with diagnostic labels or expressions of disapproval.

Few people wishing to offer support recognize that each feeling serves a specific function which separates the parent from a shattered and cherished dream. When the parents can separate, they are then able to generate few dreams. Hopefully, such new investments can incorporate the developmental disability and stimulate the emergence of a coping process. Understanding the value of the emotional states associated with grieving is central to offering parents what they need in order to grieve successfully.

Since conventional wisdom views the stages of grief as pathologic, and professionals as well as parents are influenced by such "wisdom," the following details of the grief process are offered to encourage new supportive attitudes. Denial, anxiety, guilt, depression, and anger are each presented as

constructive parts of a difficult parental growth struggle that is precipitated by an imposed significant loss.

Denial

Denial is the feeling state that is most often identified as a destructive parental attitude. Its effects can indeed disrupt early intervention or consistent treatment. This can be a problem as denial is a normal, natural, and necessary part of healthy grieving. It can be manifested in a number of different ways; however, its effect and impact are the same. Denial keeps the parent from being overwhelmed with the feelings associated with having a developmentally delayed offspring.

Parents might deny the existence of the handicap, deny the permanence of the handicap, or deny the impact of the handicap. Although each manifestation serves the same purpose, the effect and impact upon the professional can be quite different. The parent who denies the existence of the handicap rejects what the diagnostic professional has to offer. This can create tension. The professional may feel insecure and defensive about the diagnosis, or he may become quite angry at the parent who is rejecting what he believes to be an "invaluable truth." The parent who denies the disability's permanence can create all sorts of confusion in the mind of the professional. Parents may become involved in unusual interventions that traditional professionals may not easily accept. Indeed, this is a time when parents can be quite vulnerable to quackery. When a parent denies the impact of the handicap, a most peculiar alliance between the parent and the professional can occur. Such a parent can present himself and the state of the habilitative arts in such a fashion that both parent and professional will collude to deny. An example of such denial follows:

> Please understand, doctor, we are not an ordinary couple. Both of us are well educated and committed people. We have good resources at your disposal and are very aware that this is no longer a period like the Dark Ages where they locked up handicapped people and threw the key away. Why, we now have wonderful special education, terrific new specialties, and even new federal, state and local legislation aimed at enhancing the lives of handicapped people and indeed, treating them the same as everyone else. We understand that our child has Down syndrome, but we really don't feel that it's a big deal.

A professional might respond to such parents by congratulating them on their "wonderful resources and attitudes that will obviously be an asset to the child and our relationship," missing the imbedded message being shared by the parent, which is denial of the disability's significance or impact.

Most professionals will unequivocally identify denial as a serious habilitation *problem*. To do that is to violate the unity between child and parent. The stage of denial is central to a successful grief process.

We all live in a world filled with jeopardy. To live and grow comfortably in the face of jeopardy, healthy people create illusions of safety that allow them to believe that the awful things in this life happen to other people. It is impossible to prepare for terrible occurrences. Therefore, when something awful happens, e.g., when parents are confronted with an impaired offspring, they are wholly unprepared to deal with the event. Denial buys the time that the parents need in order to gain the internal strength and the external supports necessary to cope with having an impaired child. Internal strengths, often called ego mechanisms, lie dormant in a person, untested until circumstances require their presence. External supports can include: determining which friends can be relied upon, which professionals should be involved, what information needs to be accumulated (educational, legal, organizational, or conceptual—as in the learning of the new language of disability), etc. It takes an enormous amount of energy to gain ego strength and external support to face so immense a challenge. Characteristically, people who are denying are defensive and agitated, while absorbing an enormous amount of input indirectly. Yet on the surface they deny that such input is even being registered. The implications of this paradox are substantive for the professional.

The following are a series of issues and suggestions aimed at constructively facilitating the function of parental denial while supporting and reinforcing the role of the professional. At the time of the initial diagnosis it is suggested that material be presented in a concise, simple, and brief form. Seldom can parents hear much more than the child s diagnostic category. Two follow-up appointments should then be scheduled. The first should be structured to encourage the parents to call when they feel able to hear more information. The second appointment is based upon crisis intervention research that marks the six-week period of time as a significant point in crisis management (Caplan, 1964). After six weeks the most dramatic manifestations of shock reactions have run their course. At that point, professionals can more clearly see how well the parents are dealing with having a developmentally disabled child. Therefore, it is recommended that a second appointment be made on or after the six-week period. Throughout the continuing diagnostic process and through the early intervention activities, professionals can continue to share verbal and written information with the parent even though the parent might not appear to either want or use the information. It is also of value to link parents to parent organizations and parent groups, especially if such groups use peer self-help persons for support. It is important for the professional to

decide how to deal with denial. The professional who believes that it is his job to convince the parent of the nature of the disability and to persuade the parent to follow through on all recommendations may experience disappointment and frustration if the parent is denying. Rather than trying to fight the denial, it might be helpful for all concerned if the professional continues to share information, suggestions, and recommendations while supporting the legitimacy of the parent's denial around this difficult-to-accept reality.

If, on the other hand, the denial process were assaulted, and the parent were somehow forced to experience the impact of the impairment without inner strength and external supports, they would probably undergo an emotional collapse. Parents who are denying are not suffering from a logical deficiency, nor are they incapable of understanding what is being presented to them. A clinician can be sure that there are many people telling the parent that he is stupid, destructive, behaving inappropriately, or shirking responsibility by denying. The parent needs someone who accepts, even embraces, the validity of denial. There are few people who are able to give denying parents what they need most: recognition that they are loving parents who, for good reason, cannot currently engage actively in their child's habilitation.

An illustrative case comes to mind about parents who had just been told that their three-year-old was severely retarded. Neither parent showed much of a reaction. When queried about their lack of response, they answered: "That's okay, ain't none of us too smart in our family." The shocked and somewhat chagrined professional tried to explain that retardation implied much more than their concept of "not too smart." In response, the parents stated that both of them had taken a long time to learn to talk and walk and that it was obvious that this professional was overreacting and that "everything would turn out all right." The unstated goal of the professional was to get the child into a special education program. He believed that acceptance of the diagnosis was a necessary prerequisite. To his surprise, when he finally suggested that the child be enrolled in an early childhood program, the parents readily agreed "as long as they didn't call the kid no bad names." The implication of the child going to a special program was of no concern to them. However, they were not yet ready to face the emotional impact of having a "retarded child." Until the professional could come to recognize the parents' issue, he was courting a power struggle that he would surely lose, thereby depriving the child of services and debilitating his own sense of effectiveness.

Since the mechanism of denial affords the parents the opportunity to gain inner strength and to find external supports as they concern the emotional impact of having a retarded child, the denial ultimately ceases when the parents attain sufficient strength and support. Denial then ceases to exist because it has served its purpose.

Anxiety

Generalized feelings of anxiety are often evidenced by parents of impaired children while they grieve the loss of a significant dream. The anxiety is related to an important balance between the following: responsibility for the welfare of another human being and the right to have an independent life of one's own. Maintaining this balance requires many personal and internal adjustments. The event of having a developmentally disabled child disrupts whatever internal balance existed prior to the diagnosis.

Parents often report shock and dismay at discovering that *they* are their child's own medical, educational, and therapeutic manager. The child seems so vulnerable, the professionals often convey a sense of emergency, and there are conflicting messages from many different sources. There is so much to be learned, and so much seems to hinge on learning it properly. All this new pressure and responsibility is heaped upon the already existing pressures and responsibilities of the lives they lived prior to having an impaired child. Such pressure often provokes anxiety.

A mother in her mid-thirties who had given birth to a severely multihandicapped daughter candidly shared the following story, which illustrates her anxiety:

> I used to be the kind of person who would say (and sincerely believe) you do everything and anything that you can for a child, especially a child with problems. Now I'm not sure, I mean, it's much more complicated than that. Lots of times I wonder if we wouldn't all be better off if she died. You know, at times I think that we have all reduced ourselves to her level of living—just barely surviving from moment to moment, constantly struggling, using all of our energy just to get through a meal.
>
> Please don't misunderstand, no one could love a child more than I love her! It's just that my whole life could be devoted to taking care of her and nothing more. The best advice that I got from anybody this year came from a check-out girl. It was really quite simple and self-evident, but I had lost the thread and needed to hear it. She said, "You've got to continue living your own life—giving up on who you are is not helping your daughter, and it's destroying you. You have a right to a full life, too, you know!"
>
> I still haven't been able to do what she said—it's real hard. When I think of myself, I get real worried about my daughter being short-changed; when I ignore my own needs, I worry that my life is just slipping away. Sometimes the pressure gets so bad that I forget my marriage, friends, and everything, and when I see that that's happening, I get even more upset. Somehow all this pressure has got to stop!

The parental feelings of responsbility are overwhelming and the temptation to become a "professional parent" of a developmentally disabled

child is very strong; simultaneously, there are overwhelming temptations to desert. Such conflicting feelings can create circumstances rife with anxiety. The attitudes of professionals and other parents of impaired children can strongly influence the amount of pressure that a given parent feels. In truth, however, definitions of responsibility come through personal struggle. To accomplish a rebalancing of one's external responsibilities versus the maintenance of one's right to have a full life takes an enormous amount of energy and a tremendous amount of skill. Anxiety serves as an important mobilizer of energies while simultaneously focusing those energies upon the important habilitative tasks at hand.

Parents who are experiencing anxiety as part of the grieving process are in need of support from others who accept the legitimacy of such feelings. It is counterproductive to give a parent an injunction requiring that he or she "calm down." This period is one when "calming down" is not only impossible, but maladaptive, for the anxiety itself is the facilitator of the restructuring of attitudes concerning responsibility. It is also a time when realistic expectations need to be clearly spelled out, along with an understanding that parents have lives beyond caring for their impaired children.

Further, parental unwillingness to do certain habilitative activity is acceptable, and not indicative of a destructive or noncaring parent. An overstressed, overwhelmed parent ends up doing nothing, while appearing intensely involved with doing everything. Parents who can minister to themselves, and give themselves permission to reject certain aspects of the habilitative process, will in the long-run be more effective child-growth facilitators. Often a professional's overzealousness in "saving the child" will frustrate the parent's ability to resolve the anxiety phase of grieving.

Guilt, Depression, and Anger

A mystery throughout history has been the way people attain feelings of meaningfulness about their existence. The elements that go into one's personal existential significance are perhaps the most complex of our socio-philosophic and emotional concepts. Complicated and hard-to-define variables—such as capability, ethics, causality, order, fairness, potency, evaluation, morals, rewards—all weave together to create the material substance that defines one's existential purview. Any significant loss that precipitates a crisis affects this complex interweaving. Parents of impaired children find themselves restructuring fundamental issues of the meaning of life as part of their grieving process. Specifically, the feeling states of guilt,

depression, and anger assist in the process of existential restructuring (Moses, 1981).

Please note that these feeling states are inextricably interwoven; however, for purposes of understanding their individual impact upon the parent, guilt, depression, and anger will be examined as though they were separate elements. Simply stated, each feeling state corresponds to a major core element that elevates life's meaning in the following areas: commitment, competence, and justice.

Guilt is perhaps the most disconcerting of all the grief states, causing distress to both parents and professionals. Generally, it is expressed in one of three ways. The first is evidenced by parents who believe that they caused their child's handicap. Their stories often involve the taking of drugs during pregnancy, the hiding of known genetic disorders, the contraction of an avoidable disease, or other occurrences that the parents felt were under their control. This manifestation of guilt appears to be the most logical, and yet it is the least common. Because of its plausibility, it seems the least difficult to accept. The second way that parents of developmentally delayed children manifest guilt does not appear to be as logical. It is reflected through the parent's belief that the impaired child is a just or fair punishment for some specific or awful action that the parent committed in the past. There need not be any direct connection between the nature of the past "transgression" and the nature of the impairment. The third manifestation of guilt common in parents of impaired children is that of a *de facto* philosophic nature. This is reflected in the parent who basically states, "Good things happen to good people, and bad things happen to bad people." Such a general belief leaves the parent feeling guilty simply because the impairment exists.

It is hard for many professionals to accept that so painful and debilitating a feeling state can have any positive, growth-facilitating elements. In the context of grief, guilt is the vehicle that allows parents to reevaluate their concepts of causality; that is, their beliefs about how they impact the world, the validity of their morals, and the usefulness of their ethical structures. In summary, guilt helps them reevaluate the function, effectiveness, and value of their central life commitments.

Each person holds within himself a personal belief system that acknowledges control over certain events, while permitting other occurrences to be left to the whims of chance. How and when one defines certain elements as his or her "fault," while attributing their occurrences to fate, is an individual and internal process. The goal is to develop a functional system that allows one to effectively deal with the vicissitudes of life. A healthy stance on commitment avoids the absurdity of assuming full responsibility for all life events, and avoids the equally absurd position of disclaiming responsibility for anything. The guilt which parents of developmentally

disabled children experience precipitates a reevaluation of the limits of their accountability.

A useful exemplary case is that of a young couple who had two developmentally disabled children. The mother felt that the first was due to the fact that they married at a very young age. She felt that her body was ill prepared to properly carry an infant. The youngest child's disability was felt to be somehow related to the amniocentesis that she requested in order to determine if the second child was impaired. Ironically, the amniocentesis did not detect the impairment, but left the mother believing that the insertion of the needle actually caused the impairment. At the same time the father had a very different viewpoint. He had long felt rage toward his parents, rage that severed communication with them well before the birth of their first child. In some fashion that was never clearly explained, the father associated the past stresses with his parents with the disabilities of the children. It was an especially difficult issue for him to share, as he prided himself on being concrete and logical and these feelings were "so obviously illogical."

This young couple, although appearing very different from each other, were together struggling with the same issue: "Why has this happened to me?" The sensitive professional might attempt to explain to these parents the "scientific" basis for each of their children's impairments. Professionals in the early intervention areas need to be aware that guilt does not yield to argument cajoling, coercing, or even irrefutable scientific evidence. It becomes clear, indeed, that scientific explanations are extremely limited. They do not adequately touch upon "why" questions. Indeed, most scientific explanations will further the belief that such painful life events have more to do with a person's moral, ethical, and responsibility issues than with anything else. For these reasons, the best thing a professional or significant other human being can do for such parents is to sensitively listen and accept the legitimacy of guilt feelings in so painful a circumstance.

In order to work through the guilt feelings involved in having an impaired child, the parent must be able to share feelings with an empathic, significant other. The professional who fills such a role might do so by offering acceptance through an attitudinal framework exemplified by the following response: "If you truly believe that you caused your child's impairment, no wonder you feel so badly. Tell me about it." The temptation on the part of most professionals is to try to take away the guilt. Only the very exceptional person is able to validate the legitimacy of the parent's feeling without seeming to confirm a judgment of fault. To offer such a relationship is to offer a unique opportunity that facilitates growth.

Nothing will accelerate the course of guilt feelings. There are events, however, that can aggravate this difficult phase. If the professional can accept guilt as a normal, necessary, and facilitative element of grief, a more

substantial and ultimately constructive relationship with the professional will likely result. In contrast, the professional who views guilt as psychopathologic, or who has a condescending view toward parents who manifest guilt, will impair the partnership. After guilt successfully serves as the vehicle for the reexamination of attachment and impact, i.e., commital existential values, it will outlive its usefulness.

Incidentally, the manner in which the parent manifests the guilt often reflects the nature of the particular handicap. For example, many parents who have mentally retarded children connect that disability somehow to show they themselves have used their intellect in the past. For instance, a parent might say, "Isn't this an *apropos* punishment for my having wasted the intellectual skills I possess!" or "Isn't this an appropriate punishment for a person who only valued other people in terms of their intellectual prowess, and behaved condescendingly toward people who were not as bright as I." Again, it is the empathic professional who can offer the most to a parent presenting such a feeling. There is nothing to be cured or fixed. There is only a feeling state to be dealt with.

The second facet of grief that deals with one's inner existential core is that of depression. For the purposes of examining depression's impact upon grief, the rather simple definition of depression as "anger turned inward" will be adequate. One might ask, "Why is the parent of a developmentally disabled child feeling self-anger?" The answer to such a question offers some insight into the issues involved in the depression.

It appears that each human being has the need to feel competent. This need is complicated when one examines the various definitions of "competence." What does it take to be a competent father, a competent mother, a competent wife, a competent professional, or a competent anything? What it takes is indeed most personally and individually defined by the person who is struggling with the question. Further, definitions of competence change as one grows older. Therefore, definitions of competence are often different even for the same person.

Depression is the grief state that helps the parent rework a definition of competence within the context of having a developmentally disabled child. Issues of competence break down into three facets: potency, capability, and criteria for evaluation. The depressed person usually questions all of his judgments in these three areas. Such questioning is evidenced by the following "depressed" types of statements: "I am a weak (impotent), useless (incapable), and worthless (without value) human being." Parents of impaired children often view themselves as awful people because they seem to have no impact on something very important to them, something they want very much to change but can't.

Depression is generally viewed in Western culture as a pathologic state. This is unfortunate, as depression is a normal, necessary, and healthy part of

grieving. Instead of professionals supporting such feelings they generally treat the depressed person with special deference and a peculiar carefulness that often inhibits the expression of this important grief state. It would be far more helpful if the professional were able to openly accept the fact that having a developmentally disabled child is a very depressing event in the life of the parent. In truth, there is little that the parent can do to "make the child totally normal," which is indeed what most parents want to do more than anything else.

A case that dramatically demonstrates the impact of depression upon the bereaved parent is one of a woman who was an accomplished professional in the field of developmental disabilities. After many years of working in this area, she found herself in the ironic position of being the parent of a severely impaired child. When she spoke of the circumstances she stressed repeatedly that her knowledge, experience, and exposure to the field only served to show her the true limitations that existed. She felt worse off, not better off, than parents who did not have the rich background that she did. Basically she was saying that all of her education and experience were impotent, useless, without value in the face of trying to "cure" her child. And further, she was so sophisticated in the area that she even felt it inappropriate to wish for his cure as opposed to rejoicing around the assets that he still possessed. Many people around her found it difficult to deal with her since they believed that she should be "more optimistic" and "have a more positive attitude" than a less knowledgeable parent. As a result, she was not able to comfortably and openly express her depression. Instead, she adopted a cynical, hard, angry exterior that other people accepted as evidence of a determination to help her child. In truth, her inability to work through her feelings prevented her from arriving at new definitions of competence that would make it acceptable for her to have a child with the types of problems that her son had.

When she finally encountered a professional who related to the feelings of depression with support, acceptance, and encouragement, she was able to feel the anger towards self, the sense of impotence, the sense of valuelessness, and the feelings of "nothing meaning much of anything." After she explored these feelings, shed tears, permitted herself to withdraw for a period of time, and considered the meaning of her experiences, she was then able to let go of her old way of looking at things, and to allow herself to become more of an "ordinary person" than ever before.

It often takes special internal strength for the professional to sit down with a parent who feels immense depression. It takes even more strength to accept what appears to be a pathologic state. A facilitative atmosphere can grow out of statements as simple as "Tell me more about your feelings." Or "It sounds as though you feel hopeless. Do you, and if so, why?" Or "It sounds as though the birth of Johnny has turned your life upside down. Can you tell me what kinds of things have changed since his condition was diagnosed?"

Input from a professional can make a difference. Depressed people do not need cheering up. They do not need someone to deny them the right to feel depressed. Instead, they need someone who will allow them to feel the legitimate depression that they are experiencing, and further, to be available to talk with them about their sense of impotence. Unfortunately, most of us were taught to relate to depressed people in ways which inadvertently leave them feeling misunderstood, stupid, crazy, and/or destructive, in addition to depressed. Depression is part of a normal, necessary, and self-sufficient process of grieving that allows parents to separate from their lost dreams and fantasies. There is, indeed, value in "wallowing in self-pity" and "crying over spilt milk." Since what constitutes reality for each individual *is* reality *as one perceives it*, life truly is as bad as one thinks it is.

As parents are permitted to experience depression within an environment of acceptance, they will likely reevaluate their definition of fundamental competence. Such redefinition permits self-acceptance in spite of not being able to "fix their child." Again, it is the significant other who can offer an atmosphere that facilitates this discussion of grief. Quite often a professional in the field is *the* significant other.

Parents of impaired children feel anger, even rage. This particular feeling state is a most frightening one for all concerned. Most of us were raised to believe that feelings of anger are inappropriate under all circumstances. This particular attitude is most unfortunate in the context of grieving since anger is an integral facet that facilitates the struggle that parents go through to put their lives back in order.

Each person appears to have an internalized sense of justice that permits him to move within society without undue anxiety or fear. An unpredictable event, such as having an impaired child, threatens one's feelings of security about universal justice. Whenever one's sensibilities about worldly order and fairness are disrupted, one feels, at the very least, frustrated. Frustration, agitation, aggravation, irritation, and annoyance are all words that parents of impaired children find on their lips at one time or another, along with the words anger or rage. Long ago, psychologists noted that frustration leads to aggressive feelings (Miller, 1941). Parents who are frustrated by the birth of an impaired child feel anger toward that child who has intruded upon their lives and substantially disrupted them. To have an impaired child is expensive, embarrassing, time-consuming, energy-consuming, and shattering to the entire family constellation. On a more psychologically primitive level, most parents feel that all this disruption and pain has been "caused by" the impaired child.

Since anger toward children is considered heinous by most parents, they often displace these angry feelings onto others. Most commonly, spouses, the impaired child's siblings, and, of course, professionals are targets of this displaced anger. Such displacement is most unfortunate since parents are

often in need of support from the very people whom they may be alienating through their anger. As an alternative, parents may direct their anger and feelings of injustice toward God, science, or "the general order of things." They can also find solace in directing their anger into fertile areas concerned with methodological controversies concerning the treatment of their child. This type of displacement can usually elicit empathic understanding more easily from the people around them, yet it too prevents the parents from confronting the roots of their anger, the feelings of injustice that are attached to the birth of a developmentally disabled child.

A note of caution here. Professionals are ordinary human beings and therefore liable to make errors. Indeed, there are some professionals in habilitation fields whose personal motives prompt them to behave insensitively. Parental anger generated under such circumstances may be appropriate, and seems to have little to do with the anger that is part of the process of grieving. Thus, not all anger represents displacement. It is only the parental anger that seems to have little basis in reality that is likely to be displacement. Under all circumstances, whatever complaints a parent presents to a professional should be carefully listened to and examined.

Like the other feeling states of grieving, anger serves a unique function. One's sense of justice is violated when an unfair event such as parenting an impaired child befalls a person. Anger is the vehicle that permits the parent to restructure their concepts concerning justice. The parent of an impaired child who is able to incorporate the seemingly unfair event of having an impaired child "without just cause" will generate a more reality-based internal sense of justice, allowing that parent a more comfortable system that can better explain or accept life's unpredictable occurrences.

It is crucial for parents to recognize and deal with the anger that they might feel toward their impaired child. Professionals can help by accepting and relating to that anger when it is presented. This is difficult. Parents who are "reacting" to an amorphous injustice are generally easier to accept than parents who express direct feelings of anger toward their children. Professionals have often chosen the habilitation fields because of their sensitivities toward children with special problems. Many professionals become quite attached to the children with whom they work, and further, view parental anger as inappropriate, destructive, and illogical. Thus, a natural block evolves, inhibiting communication between parent and professional.

The professional who wishes to facilitate growth in the parent as well as in himself would do well to examine the role of anger in his own life as well as his feelings about parents who express anger. Parental anger in general, and anger directed toward the child in particular, is usually part of a normal, necessary, and healthy grieving process. It is important at this point to distinguish between the concept of anger expression versus the "acting out" of anger. Parents who can talk about feelings of anger with significant other

people are unlikely to act it out. When parents do act out, there are two basic forms that the anger may take. Anger can be demonstrated either through extrapunitiveness or overprotectiveness. The extrapunitive parent often couches severity within a socially acceptable context. He becomes a severe disciplinarian, demanding, and critical under the guise of helping the child overcome the emotional effects of disability. The parent behaves angrily without admitting to having such feelings or thoughts. The overprotective parent, on the other hand, disguises the feelings of anger in another manner. He maintains an attitude designed to show how "unangry" he is. "I am so loving and caring and involved in my child that I can't even discipline him, or make a demand upon him; that would look too much like punishment." Either way of manifesting anger through these acting out modes is inappropriate and most assuredly destructive for the child as well as the parent. Therefore, it is incumbent upon professionals to understand the dynamics of anger, to examine their own motives closely, and to accept a parent's expression of anger as a preventive measure against potentially destructive parental acting-out.

The set of parents about to be described serve as a good example for illustrating the anger dynamic. Both parents were in their early thirties and worked at skilled jobs in a factory setting. Their third child turned out to have a complex set of disabilities, the most serious of which was nonspecific, pervasive brain damage. These people valued self-sufficiency and were mistrustful of "college-trained" professionals. Their son's disability forced them to rely upon services offered through a university setting. In short, their child had put them into an uncomfortable circumstance that they had avoided prior to his birth. The mother presented herself in a particularly threatening fashion by constantly taking notes on anything that was said. The father sat in the background shaking his head disapprovingly and offering a passively resistant front to any suggestion or observation that was offered. The parents continually reiterated that some other high-level professional, a friend of theirs, was going to "review and scrutinize" what these "persons in training" were offering to them and their child. The tensions between the parents and clinicians were complex, continuous, and debilitating. In short, this was a disastrous parent-professional partnership.

Finally, after many months of this uncomfortable stalemate, a breakthrough occurred through the honest sharing of a physical therapist. Somehow this young woman was not threatened by these parents, but rather moved by their dilemma. One day the physical therapist talked openly to the mother, saying that she was frightened of her. She stated further that the constant note taking, critical comments, rejecting gestures, and veiled threats were making her uncomfortable. The therapist expressed the fear that it might influence her effectiveness with the little boy. The mother was surprised to

learn that she could have such an impact upon a professional and began to speak of the discomfort she had experienced at being "forced to come to this place," to feel the vulnerability of having a child that she did not understand, and further, at "being made an object under a microscope." (Two-way mirrors were common in this setting.) Gradually, more and more material was shared that essentially spelled out the unfair, stressful, unjust, and generally frustrating circumstances that confronted these parents. Imagine being forced to seek services from people whom you did not respect or trust. Suddenly, you are confronted with a team of professionals who question, evaluate, suggest, and direct you in something as personal as child rearing. The situation may engender an enormous amount of resentment. Only through open sharing, careful listening, and sensitive acceptance were these parents able to begin to struggle with their own internal ideas of what was a just or fair world.

It is the rare professional who will be able to recognize that parental anger is part of grieving and should be accepted and facilitated. Yet, if the professional can tolerate the displacement of anger and/or the parent talking negatively about the child, such interactions are very helpful. Parents who are able to talk with significant others about their anger are less likely to become either extrapunitive or overprotective. If allowed expression, if seen as acceptable, if indeed incorporated as part of the normal process of grieving, the anger of parents of developmentally disabled children may be used to restructure their internal sense of justice and thereby help them to move to higher levels of functioning.

Attitude change in parents is facilitated by the three feeling states of guilt, depression, and anger. These three grief states precipitate a struggle with the existential values that people continually rework in the face of substantive loss, i.e., primary significance and meaning, definitions of human competence, and internal sense of order and justice. Attitude change then serves as the prerequisite for active coping with the impact of the disability.

The Parent-Professional Relationship as Significant Grief Facilitator

The grieving process as described is a feeling process that permits the parent of a developmentally disabled child to separate from dreams and fantasies generated in anticipation of the birth of that child. The inability to successfully separate from such a dream is devastating to both parent and child. If the parent does not generate new dreams that the child can fulfill, then each day the child will be experienced as a disappointment and a failure

in the eyes of the parent. This parental disappointment will ultimately be communicated to the child, leaving the child feeling as though he or she is indeed a source of pain to the parents. If, however, the parent is able to separate from the dream, there is the distinct possibility that the child will be accepted for who he or she actually is. Such acceptance is an important prerequisite of attachment, and full attachment is a prerequisite of overall development and growth (Brazelton et al., 1974). It is within this context of development that the concept of facilitating grief becomes an important tool in the intervention and habilitation of developmentally disabled children.

How do parents survive the loss of a profound and central dream shattered by an impairment? How do parents grow from such a trauma and become enhancers of their child's life as well as of their own lives? The answer appears to lie in working through grief in the context of meaningful human relationships. A meaningful relationship is defined as one that gives a bereaved person the human environment in which to feel and share the potent emotions of grief. Grieving is a constellation of feeling states (denial, anxiety, depression, anger, and guilt) that facilitates a personal reorganization, thereby fostering dramatic changes that permit serious loss to become a life-enriching occurrence. To truly help in the growth process of a child, the professional must attend to the grief struggle experienced by the parents. The professional who understands how children develop will accept the legitimacy of Holistic conceptualization, including the parent as part of the monolithic unit called "child." The ideal circumstances for habilitating the developmentally disabled child, therefore, are those where the parent can rely upon the professional to offer a meaningful and significant relationship necessary for successful grieving.

There are a few basic concepts and guidelines that can aid in the sharing process between a professional and a parent, while still maintaining the professional integrity demanded of specialists in the fields. The following suggestions are not offered as "psychotherapy" components, but rather as fundamental elements that can help both professional and parent to positively affect the feelings indigenous to grieving:

1. Maintain a vigilant awareness of the dynamics of grieving; it is easy to forget the process of grief when faced with intense emotion.
2. Review your own personal strengths and weaknesses around grieving past significant losses of your own.
3. Clarify, maintain, and practice focusing on the differences between a feeling and an action. Many actions can be immoral, illegal, unethical, insensitive, and inhumane; feelings are synonymous with being alive, central to dealing with loss, and, therefore, exempt from judgment or criticism.

4. Try to avoid answering direct questions that are of a general or predictive nature, because parents are usually not interested in the answer half as much as in having their concern heard.
5. Try to remember you are not universally responsible for correcting the child's disability, nor the disruption that the disability brings to the family. Limit your concerns to the areas that are consistent with your professional role and expertise.
6. Try to separate the content statements from the feeling statements that are both received and sent by you. It helps to maintain consistency in the modes of communication between parent and professional.
7. Throughout your interactions do not ignore or abandon your professional convictions, recommendations, or programmatic structures; the direct habilitative services offered the developmentally disabled child are always the first priority.

A Personal Note to Parents Only

There is no debating that the parent is unquestionably the most vulnerable person in the parent-professional relationship. That fact, however, does not free the parent of all responsibility for this important partnership. There are some basic prerequisites that parents need to accept if they are going to influence this working relationship in a positive fashion.

While it is clear that successful grieving requires open sharing, there is a decided difference between an emotional presentation of self versus acting out feelings. This distinction is readily seen when children are told, "It's okay to say that you're angry about something, but it's not okay to hit!" With adults who are grieving while simultaneously trying to "work with" the source of their grief, the acting out does not usually take the form of hitting. It is far more subtle than that. Making appointments and not showing up, playing professionals against each other, presenting oneself as less capable than one really is, playing "yes, but..." as a way to close down communication, holding grudges while never confronting the "accused professional offender," etc., are some examples of parental behavior that are devastating to parent-professional relationships. Generally, most professionals are hard-working, underpaid, sensitive people who are genuinely struggling with the same child who is offering you so much difficulty. They truly need your advice, suggestions, and help, but will have the same negative reactions to rejection, criticism, and emotional assault as you would, were they to behave that way toward you. All of this describes basic "Golden Rule" human relations that all readers probably know, but that under the circumstances of grievous pain can easily be forgotten.

If the relationship between parent and professional is truly to be a partnership, then the parent also needs to understand some of the dynamics that influence professionals involved with developmental disabilities. Persons attracted to work in the habilitation fields are not usually influenced by the same factors that attract other people to other areas of work. Most certainly, they do not pursue careers in these areas for money, prestige, or power—three of the primary motivators in many other types of work. What does attract people to this work? There is scant research documenting the motives that bring people to the habilitative fields. However, an informal survey of a number of professionals seems to indicate that a larger-than-ordinary proportion of professionals in the habilitative fields are themselves directly involved with a family member who suffers from a developmental disability. That is, they are the sibling, child, or parent of a developmentally disabled person. Further, many of these individuals show a high degree of sensitivity toward the plight of "underdogs."

Diagnosticians, teachers, therapists, aides, etc., have a "burn-out" rate that is substantially higher than attrition rates in nonhabilitation fields (Presley, 1982). Caught between the pressures presented by the child's needs, administrative accounting, parental demands, peer pressure, and their own professional ideals, many professionals have become discouraged and disillusioned with their work. Indeed, the collision between their dreams and fantasies about work, and the severity of a reality filled with pressures and disappointing limits often precipitates a grief response in professionals. If both parent and professional are, at times, suffering with similar issues, then a "rotating magnets" phenomenon can take hold; intense attraction or repulsion can happen from moment to moment. Parental sensitivity to professional stresses can enhance this important partnership. Professionals need the same acceptance of their feelings that parents do!

It is pointless for either parent or professional to try to become "grief diagnosticians," since the feeling states previously described are not experienced in any particular order, nor are they mutually exclusive. That is to say, people feel what they are going to feel when they are going to feel it, and often have two or more feelings simultaneously. Moreover, an attitude of acceptance aimed at facilitating grief would be damaged by an attempt to diagnose a person's grief state, since diagnosing is, by definition, a process of labeling.

The grieving process is far from a one-time occurrence. Parents of developmentally disabled children repeat and rework the feeling states as the child matures. All parents seem to grieve at the point of initial diagnosis. In addition, each time the child comes to a major milestone that impacts the parent in a new way, grief will once again be experienced. Common developmental points that reactivate grieving are:

1. When the child reaches "regular" school age (for that is a time when comparison between children occurs).
2. When the child reaches puberty (and offers all the dilemmas of adolescence, plus the complexities of the handicapping condition).
3. When the child reaches high school graduation age and the disability negatively affects the child's ability to move on to a more independent manner of functioning.
4. When the child reaches an age where the expectation is that he or she will indeed live totally independently (working, getting married, etc.)
5. When the parents reach retirement age and the nature of the disability is such that the child might interfere with their retirement and require that arrangements be made for the time after their death.

Coping

Since grieving is almost entirely an emotional process, it is clear that there are other processes that occur simultaneously, or in tandem with grieving. The general term of "coping" covers most of the remaining activities that require interaction among the parent, the child, and the professional. Although much has been written since 1960 about the coping process, the most succinct and clear descriptions and definitions of the process were offered by a rehabilitation psychologist named Beatrice A. Wright (1960). In her book, *Physical Disability: A Psychological Approach*, Wright highlighted four major coping processes. Each of these impact the parent in such a manner as to precipitate a change in the value system. The four coping mechanisms are: containing the disability effects, devaluing physique, enlarging one's scope of values, and converting from comparative values to asset values.

When parents first begin to deal with the impact of having a developmentally disabled child, their tendency is to generalize the effects of the disability. They are prone to see the entire life of the child (and often of themselves) as ruined. It is not uncommon for parents to say things like, "My child will never marry; my child will never work; my child will be dependent upon me for the rest of my life." They conceptualize the worst, and then deal with reality. Confrontation with reality is aided by accepting the limits of the effects of the disability. Containment is an attitudinal process. That is, the parent does not permit the concept of disability to contaminate those aspects that need not be affected by the disability. The professional can be extremely helpful during this facet of coping by offering as clear or concise an assessment or diagnosis as possible, particularly an assessment that emphasizes the competencies and assets that are *not* affected by the disability.

If parents can be exposed to functioning impaired adults, it will help with this coping process.

The devaluing of physique, as a coping mechanism, attacks one of the more painful blocks to successfully dealing with handicapping conditions. Western culture seems to place high value on physical attributes, oftentimes judging people according to appearance. Unfortunately, most handicapping conditions are seen as ugly. Specifically, "different" behavior, mannerisms, and peculiarities of gait, speech, or language unique to developmental disabilities are often viewed negatively. The coping mechanism of devaluing physique deals with this issue. Physique is broadly defined here as any detectable manifestation of the disability which might be judged negatively. One has successfully coped with the issue of physique when one has adopted a value system that focuses on those qualities and competencies associated with being human and that ignores or devalues surface qualities.

Enlarging the scope of values works on the premise that most people narrow their value system, experiences, interests, and associations as they grow older. This appears to be true for a great many people. Such narrowing poses a special problem when one has an impaired child whose disability precludes participation in the particular confined lifestyle that the parents have chosen. In order to facilitate the child's growth, the parents must be able to enlarge their scope of values in order to genuinely accept whatever lifestyle the child might pursue. Such an exploration requires parents to examine their own values about what constitutes "the good life." If this process does not occur, then both the parent and the child will feel as though the child's lifestyle is, at best, second-rate and unacceptable.

The last method of coping involves the issues of comparison and competition. Western culture emphasizes winning, doing better than the next person, and comparing one person's performance to another. Such a comparative atmosphere can be uncomfortable for many nonimpaired people. A comparative atmosphere is particularly devastating to impaired individuals and their families. The parent must understand that how one compares with others is far less relevant than the mastery of a skill or the demonstration of a competency. Ultimately, to cope with the child's disability, the parent comes to value the child as he or she is, respecting each new achievement as an asset, without making a comparison with other children. It is through this process that the parent learns to first appreciate the child, and then to focus on the handicap.

Clinical Implications for Initial Diagnostic Period

1. Initial diagnostic feedback sessions need to be concise and simple. Efforts must be made to determine what the parents actually heard and understood. This helps to deal with the response of denial.

2. The second feedback session (scheduled as soon after the first as possible) focuses upon medical, educational, and therapeutic treatment methods. Ideally, details are presented in response to parental questioning.
3. Avoid directly confronting overt resistance or indirect denial; it's useless to do so and compounds the denial process. Instead, use humor, paradoxes, gentle coaxing, pleas, or "soft" persistence to serve the child without disenfranchising the parent.
4. Resist the impulse to calm, uplift, soothe, or disarm the emotionally stimulated parents; permit them to express their grief!
5. Consider the three-part parent program outlined below:
   - *Parent education*, consisting of imparting the necessary medical, educational, therapeutic, legal, and psychological information concerning the child.
   - *Parent support groups*, consisting of meetings focusing on the sharing of emotions affecting the parents.
   - *Parent training*, consisting of sessions where the parents gain skills needed to directly enhance their child's growth.
6. Maintain support groups for diagnostic professionals. Working with families at the early stages of disability is stressful work; don't do it alone!

Summary

The growth and development of impaired children requires attachment, nurturance, and stimulating interaction from care givers. Parents are, most commonly, the primary care givers for their children. They hold the keys to their child's successful development. Professionals in child habilitation must conceptualize the parents and their child as one unit.

The diagnosis of a developmental disability for a child precipitates grieving in the parents. The process of grieving can allow the parents to constructively incorporate the emotional impact of the disability, thereby facilitating the coping behavior desired by professionals. Successful grieving depends upon significant human relationships that support the process. Parent-professional partnerships benefit the child when the partnership attends to the significant human elements of grief.

It is the unconditional acceptance of denial, anxiety, guilt, depression, and anger that constitutes the most positive relationships between parents and professionals. Good working relationships foster attitude changes that prompt coping behavior and, therefore, meaningful strides toward the child's habilitation. The parents who are actively gaining from the process of

grieving and coping shift their attitudes. This is best exemplified in the following quote: "At first all he was to me was an impaired child; now he's a child who's impaired!"

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Coping with Loss and Change
Activity/Handout 3A
Lecturette and
Large Group Discussion
20 minutes

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Grieving Over the Lost Dream

by Audrey T. McCollum

Parents grieve for themselves in their state of loss.

In pondering the meaning of loss, the religious philosopher Kierkegaard wrote, "Despair is never ultimately over the external object but always over ourselves. A girl loses her sweetheart and she despairs. It is not over the lost sweetheart, but over herself without the sweetheart. And so it is with all cases of loss . . ."

To understand the losses we experience when our child's health is sufficiently impaired to affect the quality of his/her life—and our lives as parents—it is useful to think first about why we ever choose to have children.

Choosing To Be A Parent

There are many different things that motivate us when deciding to have children.

A couple may want to emulate their own parents—to parent a child as they were parented—and vicariously to re-experience their happy childhood years.

Conversely, new parents may desire to compete with their own parents, to care for a child as they wish they had been parented. They may want to give their child what they never had, whether in affection, opportunities, or material goods—and vicariously to experience a childhood they never had themselves.

Men and women may want to prove their sexual adequacy by producing a child. Or, they may feel destined or pressured by their ethnic or religious beliefs to bring forth a child to perpetuate the race or the family name.

They may be trying to give meaning to lives that seem empty and without purpose. Some people have children because they are seeking a form of immortality. We all share a wish to survive our own deaths by leaving an imprint on the world, often in the form of our own children.

Or, men and women may simply wish to nurture, to shape guide and cherish another life—their child's.

Expectations

Any of these motives (and there is usually a mingling of several) contribute to the daydreams we have about our offspring. We dream about the child—how s/he will look, feel, sound, behave. We dream of the teenager and adult—who s/he will be, what s/he will be—gentle or boisterous, dainty or virile, artistic, intellectual, athletic, political, a professional football player, a famous author, a brilliant scientist, an astronaut.

Usually, parents and their offspring interact in such a way that gradually parent's dreams and expectations are modified by recognition of their child's actual capabilities. As the fantasy of the dream child is replaced with day to day living, parents will hopefully accept the child for what he or she is and wants to be.

When a child's health is impaired, parents can be confronted harshly and abruptly with a reality that allows little or no hope for fulfillment of their dreams. A child with muscular dystrophy is not likely to become a pro football player; a child with Down syndrome is not likely to win a Nobel prize.

So the fantasied child is lost and a process of grieving begins. Of course, most parents do feel genuine sorrow for the child whose health is impaired. But, parallel to that, as Kierkegaard reminds us, parents grieve for themselves in their state of loss.

Grief

Acute grief can have strong physical manifestations. It may include shortness of breath

and frequent sighs, loss of appetite and empty feelings in the abdomen, lack of strength and feelings of exhaustion, along with restlessness and aimless activity, a loss of warmth and detachment from other people, irritability, anger, and guilt.

These, then, are normal responses to the sudden, total loss of a loved one. In my experience, they are also felt by parents of children found to have significantly impaired health, whether physical or mental. Their grief gains momentum when the diagnosis of the disability or disease really begins to sink in.

Most such parents experience depression. I am not speaking of a pathological reaction, an illness, but of depression as an expectable response to significant disappointment and loss—the loss of a dream. I am speaking of depression as it has been viewed by psychoanalyst Elizabeth Zetzel. It includes depressive emotion which is "a sense of lack of nourishment, fullness, warmth, energeticness." But depression is more than a cluster of emotions. It is a psychological state marked by helplessness and loss of self-esteem.

Self-Esteem

In the parent of a child with a disability, loss of self-esteem comes from many sources.

From the time we begin thinking of conceiving a child, most women and men have doubts about the outcome. But these are usually dispelled by the assumptions we make about our capabilities, often without much conscious thought.

Most of us expect to contribute unflawed genes to the embryo which will cause it to develop into a healthy baby. Both parents expect themselves to surround their child with a cocoon of care and protection to ensure its happy and healthy development, to ensure the fulfillment of at least some of their daydreams.

A child's impairment, whether inherited or acquired confronts us with a sense of having failed to live up to our expectations. We are helpless to undo the faulty development, and our sense of competence and self-regard can be shaken drastically.

Loss of self-esteem is fed by guilt. Most parents painfully review any acts of omission and commission that might have caused the child's impairment. We review our thoughts and feelings as well. Any negative feeling about the pregnancy or about the child before her or his problem developed can seem unforgivable. A parent can experience guilt and remorse over any mixed feelings.

Only secretly do parents allow ourselves to recognize the anger we feel at moments toward the disabled child because s/he is afflicted. Such anger can feel totally unacceptable.

All too readily we find cause to accuse ourselves, since we are all imperfect. When the sense of guilt is unbearable, it may be expressed as hostile blame of others—doctors, nurses, our own parents, and quite often our spouses.

Even as the hostility is felt and expressed, the internal critic that operates in each of us—our conscience—may judge the hostility to be unjustifiable, even unforgivable. How can we feel that way towards our *own* children? So from still another quarter, the self-esteem is lowered.

From a sense of inadequacy or blame, feelings of helplessness, guilt, and hostility, the boom is lowered on our faltering self-regard. Depression enfolds us.

The intensity and the duration of our grief and depression will vary. Each new major disappointment and loss that we experience through a lifetime tends to re-kindle the feelings associated with earlier losses and disappointments. For example, the birth of a baby with brain damage may unconsciously revive all the sadness, frustration, helplessness and rage associated with the terminal care of our own parent after a stroke. The feelings about the baby in the present are greatly reinforced as they are fused with the feelings about the parent in the past. There is always some chain of connections in our experiences.

The consistency of our self-esteem varies among us. Self-esteem is nourished in childhood by our parent's love and acceptance; it is shaped by their expectations of us, and our capacity and desire to meet those expectations. Self-esteem reflects the congruity or the incongruity—the fit, in other words—between the ideal self we aspire to be and the actual self we experience in reality. When we have come to accept both our limitations and our capabilities, when our ideal selves are in reasonable harmony, our self-regard is likely to be secure and resilient. It can absorb some bruises.

Those who lack adequate nourishment of their sense of goodness and worth, and who have transformed critical judgements from others into harsh self-judgments; those who cling to ideals of power and perfection and who depend on extraordinary performance and external recognition to feel worthwhile—such people have precarious self-esteem. When gaps between their ideal and actual selves are exposed, when they are threatened by helplessness, they plunge. In such people, normal feelings of depression which everyone feels from time to time, may develop into depressive illness.

Experiencing Pain

Some parents are unable to tolerate the grief and depression precipitated by their child's affliction.

Sometimes, there actually may be an absence of grief. Although to outsiders this may seem to express courage (smiling in the face of adversity, keeping a stiff upper lip), in fact, it does not serve the parent of the family well at all. When the conscious experience of grief has been postponed, it is likely to erupt unexpectedly and inexplicably at a later time. Or it may be completely avoided, but the avoidance can draw the parents' emotional energy away from family and friends. A parent may become distant and detached, absorbed in work and emotionally unavailable to the other spouse who may want support for his or her own struggles with the situation.

"Blessed are those who mourn, for they shall be comforted." Even those who can tolerate their grief and depression proceed with the work of mourning slowly and unevenly to protect themselves from being overwhelmed, and to preserve their capacity to function in daily life. Grief can smoulder, to be rekindled again and again. Each time it flares, steps toward mastery can be taken.

The anger can be recognized and vented in appropriate ways. The sense of guilt and disappointment can be explored and expressed so that harsh self-accusations can gradually yield to self-forgiveness.

There can be a gradual giving up of the attachment to the lost dream—the dream of a fantasy child—and a reconciliation with the reality of the actual child's impairment.

The sense of helplessness can be examined. What cannot be modified can be accepted for what it is, but this acceptance can be paralleled by the mobilization of problem-solving efforts on behalf of the child and the family.

It is now well recognized that psychological growth and development continue throughout our life times. We bring to each new crisis the unresolved conflicts and the emotional baggage from our past. But each new crisis involves the reopening of a book, so to speak, and the chapter endings can be rewritten.

Grief is intensely painful. But psychological distress that is experienced and mastered results in the growth necessary to deal effectively with life's adversities and also to experience its joys. The lost dream can be transformed into a new vision. ■

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The Professional's Dilemma: Learning to Work With Parents

by Milton Seligman and Patricia Ann Seligman

If professionals do not understand the sources of their own stress, then they may prematurely label parental behavior rather than understand it.

Attention has been focused on children with disabilities—their characteristics, learning and behavioral styles, as well as their medical and educational needs. More recently, an increased awareness and understanding of the families of these children has occurred, with particular emphasis on the impact a disabled child has on the family.

As a consequence of this heightened study of exceptional families and their circumstances, the relationship between families and the professionals from whom they seek help has come under scrutiny. Although we need much more information about the nature of parent-professional relationships, especially from a research perspective, there are indications that this important partnership is sometimes less than satisfactory—especially from the parents' point of view.

Collaborative relationships, whether between husband and wife or between parents of children with disabilities and professionals, are dependent on the positive contributions of both parties. From this perspective, when parent-professional relationships are poor we can assume that both parties contribute to the situation. Therefore, both parents and professionals must work to improve their relationship.

In the past parents were usually held responsible for all difficulties. Although parents do contribute to difficulties, we hold that the "expert," because of professional training and vocational commitment, must bear the major responsibility for developing positive working relationships.

To establish a positive working relationship with parents, professionals need to understand 1) the impact of professionals on parents during the search for help, 2) the impact of the child with a disability on the entire family over an extended period of time, and 3) the impact that the child and the family have on the professional.

Impact of Professionals on Parents

Problems can emerge when the parents have their first meeting with a professional. The parents may have consulted or contacted a variety of "experts" before this meeting. At the end of the consultation they may also indicate that they intend to see yet another expert. Professionals often label this behavior as "shopping around." They often feel that shopping around is an indication of the parents' denial of the child's problems. They believe that parents are endlessly searching for a favorable diagnosis or or an optimistic prognosis. This labeling may obscure the professional's understanding of the parents' behavior.

Actually, parents may consult other professionals for perfectly legitimate reasons. They may wish another opinion, or may want to have the initial diagnosis and current program reviewed. For some parents, going from professional to professional may be precipitated by the changing needs of their child. Also, many parents feel they have been treated with little respect in the past. They may be seeking professionals who have the required expertise *and* who treat them as human beings.

Impact of Child With a Disability on Family

We believe that it is wrong to ignore the strain a disabled child places on the family. It is equally wrong to consider this situation as significantly different from the effect any tragic event has on the family unit. The difference, however, is the

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chronicity of the strain (if in fact the family reacts with strain) of having a disabled child, as opposed to the more short-lived traumas that are part of everyday family life.

Everyone needs time to adjust to problems that may be chronic. Some turmoil is common during adjustment. In any event, a professional conclusion that turmoil means the family is emotionally unstable reflects a jaundiced and negative view of families who happen to have a child with a disability. Research has illustrated the phases that families go through as they adjust to the child's disability. It is necessary for professionals who work with parents of disabled children to understand coping mechanisms parents use during the different adjustment phases. Variation from these patterns may reflect problems which require psychological help.

Some professionals assume that all exceptional parents have difficulty accepting their child and they feel this is unhealthy. The key word here is "unhealthy." Knowledgeable professionals would consider the lack of acceptance, assuming that it is accurately assessed in the first place, as a natural reaction when parents first learn of their child's exceptionality. It is important for professionals to be able to distinguish between the lack of acceptance, when it occurs early, and long-term denial, which may indicate that some type of counseling is needed. In both instances exceptional parents can hardly be considered emotionally disturbed but, similar to a recently divorced spouse, they need time—and sometimes counseling—to become accustomed to the new situation.

Parents may feel depressed when they first learn about the child's difficulty. Professionals sometimes attribute these feelings to the process called "internalization of unacceptable hostility or death wishes toward the disabled child." I.e., the feelings of anger parents can have toward the child are so upsetting that they deflect these angry feelings toward themselves. The assumption is that turning anger toward oneself leads to feelings of depression. Such thoughts and feelings occur to all parents, not only those of disabled children, and these feelings do not necessarily constitute unhealthy reactions. Here again the professional needs to distinguish ordinary, temporary depression from chronic depression where professional help is needed.

Some parents are afraid of letting anyone else take care of their youngster who has a disability. This makes it difficult for the parents to have any time to themselves and it can make it difficult for the child to learn to work with other people.

This behavior has been labeled "parental overprotectiveness" by professionals and has been attributed to repressed hostility toward the handicapped child. According to this theoretical explanation, the parent feels angry toward the child for being disabled and/or for being difficult. Because hostile feelings are unacceptable, they are pushed out of awareness, only to resurface as the exact opposite of hostility—overprotectiveness.

This explanation of parental overprotectiveness is but one of several possible explanations for this behavior. Professionals may misconstrue realistic protective measures as parental overprotectiveness. Even when the behavior is inappropriate, it would also be more productive for professionals to focus on the behavior—overprotectiveness—to help parents understand the potentially harmful effect it may have on their child. This approach would be more effective than to view it as an emotional disturbance.

Professionals are just as liable to feelings of denial as are parents.

Impact of Child and Family on Professionals

Working with the pain and anguish that parents and children with disabilities experience arouses intense feelings. We have already discussed the impact of a disabled child on the family. Yet the impact of the child's difficulties on professionals and the ways it can affect their work is often ignored. If professionals do not understand the sources of their *own* stress, then they may prematurely label parental behavior rather than understand it.

Research tells us that societal attitudes toward those who are "different" in some way tend to be negative. Not surprisingly, the response of professionals toward those they serve is not always positive. Negative attitudes are often transferred into stereotypes—distorted, erroneous and rigid views of a particular group of people.

Our own subjective feelings are not always clear to us. Yet the more aware of our "inner experiencing" we are, the better we are able to modify negative feelings that can interfere with collaborative relationships. For example, it is useful to be able to distinguish between subjective feelings of empathy (truly understanding someone else's circumstances) from feelings of sympathy (which can be characterized as a feeling of "you poor thing"). Professionals who consistently experience feelings of sympathy, pity, fear or hostility toward parents of disabled children should consider another field of endeavor.

Other feelings that professionals can have, such as hopelessness and disgust, are difficult to keep

hidden from parents and can have the effect of generating similar parental feelings toward their child. These reactions are often the consequences of insecurity the professional feels. For example, the professional imagines how it would be to be in the parents' situation and concludes that it would be difficult, if not impossible. He then communicates his feelings of hopelessness to the parents.

As a result of the multiple disabilities a child may have and the difficulty the family experiences in dealing with the situation, the professional may truly feel helpless. A professional can recognize his or her own feelings and discuss the situation (both the parents' circumstances and his feelings in working with the parents) with a respected colleague. Another possibility, which requires much tact and sensitivity, is a referral to another professional who is in a position to be more helpful.

Professionals are just as liable to feelings of denial as are parents. For example, because of personal feelings some professionals are unwilling or unable to recognize and acknowledge children's difficulties. This can leave the parents uncertain, more anxious, and unwittingly contributes to parental denial.

In some circumstances, especially when a difficult birth has occurred, a professional (e.g., an obstetrician) may feel that he has contributed to the child's problem. Such feelings of guilt may, in some subtle ways, interfere with productive parent-professional relationships.

For many of the reasons we have discussed, some professionals consider parents more of a nuisance than a resource. Parents are seen as persons who have lost their objectivity and who therefore possess distorted perceptions of their circumstances and their child. These professionals believe that since they are specially trained and are being paid for their expertise, only they can give profound, expert opinions. Although parents ordinarily have high expectations from service providers, this expectation has some negative consequences when professionals are reluctant to consider the opinions and perceptions of parents worthwhile.

When considering a particular family situation, often the most useful vantage point is that of the parent. It would be extremely beneficial if professionals would value the parents' perspective about a particular child and family. It is necessary for the professional to view parental perceptions as adding to the information they already have, instead of considering them contradictory. Professionals who base their evaluations on the information received from other professionals, their own observations, the child, *and the parents* are in the strongest position to be helpful.

Professional Training Needs

Professional training programs generally ignore the possibility that those they educate may be only minimally effective; professional training does not make the professional immune to stereotypic thinking. In fact, a major contributor to stereotypic/prejudicial thinking is the professional literature, especially the early literature related to disabled children and their parents. As an illustration, mentally retarded children were commonly referred to as defective and both children and their parents were, and to some extent continue to be, characterized by their deficiencies. Little regard was given to their strengths as individual human beings. Nor does professional training make professionals immune to the stresses we have discussed earlier in this article.

One way to deal with these problems is to recognize and admit to them. Without self-awareness little change in attitude can occur. Enlightened professional programs can include seminars, workshops, and other small group experiences designed to explore the notion of stereotypes as well as examine the specific prejudices held by the participants of these educational experiences. Small discussion groups where one can safely talk about stereotypes tend to be useful. Also, interaction with disabled children and adults and their families can help to reduce stereotypes.

The professional issues we have discussed here are just part of the problems that occur in this phase of designing new ways to work together. Just as we have made progress in getting parents and professionals to work together, we remain optimistic that these barriers to effective communication can be overcome. ■

In any event, a professional conclusion that turmoil means the family is emotionally unstable reflects a jaundiced and negative view of families who happen to have a child with a disability.

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Coping with Loss and Change

Summary

Parents experience a wide range of emotions as they adjust to having a child with a disability. These states of coping are all part of a normal, long-term process of dealing with the "loss of a dream," i.e. the dream of having a normal child. Each parent goes through the process in his/her own way and at various times during the life of the child.

Shock:	the normal reaction to finding out that a child is handicapped.
Denial:	the psychological mechanism which protects parents from the overwhelming pain and disappointment that go with the news that their child has a disability.
Guilt:	the phase when parents can no longer deny the reality of their child's disability and question what they did to cause it.
Anger:	the phase when parents ask "why," seek someone or something to blame, and feel bitter toward professionals and other parents whose children are "normal".
Sadness:	the phase when parents experience the sense of loss frequently associated with grieving a death.
Objectivity:	the phase when parents begin to explore the nature of the disabling condition and persons/programs for assistance.
Maintenance:	the idealized, final phase when the parents accept the limitations of their child's disability, and separate these effects from the child as a person.

Successful grieving requires being able to share feelings with another person or persons. No two people have exactly the same experiences or feelings, but there are commonalities and it is healing to be listened to and heard.

Successful Sharing Process

E - Empathy

N - Non-Judgmental

U - Unconditional

F - Feeling Focus

Empathy:	sharing the accurate perception of another's experience.
Non-Judgmental:	absence of positive and negative judgmental elements.
Unconditional:	without condition; respect, value and care about a person's plight because he/she exists.
Feeling Focus:	focus on feelings, not actions, facts, or other "content"

All persons experience grief in their lives, including the professionals who provide services to children with disabilities and their families. Professionals can assist parents best when they separate feelings from actions and/or factual statements, and remain focused on the direct services they have the expertise to provide to the child.

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Evaluation

Your responses to the questions/statements below will assist us in improving this module. Please respond to all items. Your participation in this evaluation is completely *anonymous*. DO NOT place your name anywhere on this evaluation.

Based on a scale of 1 through 10, how much of the information presented was new to you?

_____ 1 is not much new; 10 all new.

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
1. After this session, I am familiar with the states of coping.	1	2	3	4	5
2. As a result of this session, I understand that the states of coping are common to all individuals.	1	2	3	4	5
3. This session helped me relate the states of coping to my own personal experience.	1	2	3	4	5
4. Because of this session, I recognize that the process of coping is normal and each individual experiences it differently.	1	2	3	4	5
5. After this session, I am familiar with Ken Moses and his work.	1	2	3	4	5
6. The material presented was sensitive to all cultural groups.	1	2	3	4	5
7. The material covered information which was appropriate to all handicapping conditions.	1	2	3	4	5
8. The material presented matched my needs.	1	2	3	4	5
9. I will use some of the information/resources that were introduced.	1	2	3	4	5
10. The instructors did a good job.	1	2	3	4	5

11. Specific suggestions to improve this module:

_____

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